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Citation for published version:

Jenkins, N, Lawton, J, Douglas, M & Hallowell, N 2013, 'Inter-Embodiment and the Experience of Genetic Testing for Familial Hypercholesterolaemia', *Sociology of Health & Illness*, vol. 35, no. 4, pp. 529-543. <https://doi.org/10.1111/j.1467-9566.2012.01510.x>

Digital Object Identifier (DOI):

[10.1111/j.1467-9566.2012.01510.x](https://doi.org/10.1111/j.1467-9566.2012.01510.x)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Sociology of Health & Illness

Publisher Rights Statement:

Jenkins, N., Lawton, J., Douglas, M., & Hallowell, N. (2013). Inter-Embodiment and the Experience of Genetic Testing for Familial Hypercholesterolaemia. *Sociology of Health & Illness*, 35(4), 529-543 doi: 10.1111/j.1467-9566.2012.01510.x

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**Inter-embodiment and the experience of genetic testing for familial
hypercholesterolemia**

Abstract

In this paper, we explore the concept of inter-embodiment and its potential for advancing sociological research into illness biography and genetic identity. Inter-embodiment views embodied knowledge as produced through relations between bodies, as opposed to originating from within the body or as the product of relations between dis-embodied selves. Drawing on our qualitative study, in which we interviewed 38 participants about their experiences of discovering high cholesterol and undergoing genetic testing for familial hypercholesterolemia (FH), we discuss how their narratives may be understood from an inter-embodiment perspective. Participants frequently talked at length about their family histories of high cholesterol and/or cardiovascular disease. Through these accounts, we develop the concept of the family corpus in order to highlight the role body-networks play in shaping lay constructions of genetic identity and familial disease biography. The family corpus, we argue, is useful in understanding why participants experienced genetic testing for FH as either biographical re-enforcement (Carricaburu and Pierret 1995) or as biographical disruption (Bury 1982). We conclude by discussing the implications of our findings for future sociological research into illness biography and genetic identity.

Word count

Abstract: 181

Main text incl. bib (excl. acknowledgements): 7,504

Table: 250

Total: 7,935

Introduction

Since the 1980s, two important bodies of work have come to take centre stage within the sociology of health and illness. The first has concerned itself with exploring the impact which the onset of chronic illness can bring to bear on patients' biographies (Lawton 2003). Early research in this area has led to an implicit focusing on the body, not just as the host of disease, but as the landscape upon which illness and identity are experienced. The second tradition, the sociology of the new genetics, has focused on exploring the socio-ethical and political implications of the rise of genetic medicine (Conrad and Gabe 1999). Research in this area has sought to explore (amongst other things) the impact of genetic testing on selfhood and on family relationships. By drawing on in-depth interviews with patients diagnosed with a hereditary form of hypercholesterolemia, this paper will seek to explore how inter-embodiment - the notion that embodied knowledge is the product of relations between bodies - can aid research within these two traditions.

Sociological research into illness biography owes its greatest intellectual debt to the seminal work of Bury (1982) and his notion of biographical disruption. Bury developed this concept in order to demonstrate how the onset of chronic illness (rheumatoid arthritis) fundamentally throws the individual's sense of self, their relations to others and their lifecourse trajectory into question. Whilst biographical disruption has become one of the most widely appropriated concepts within the sociology of health and illness, one of the less widely recognised contributions Bury makes in his early paper is to show (albeit implicitly) how biographical disruption is firmly located within patients' embodied experiences of ill health. According to Bury, experiences of pain and discomfort caused by the onset of rheumatoid arthritis

(RA) may provide the catalyst for biographical disruption, as these early symptoms can take over the individual; their intensification gradually compelling their acknowledgement, disclosure and the seeking of medical assistance. Experiences of pain and impairment can lead, following Bury, to the posing of fundamental questions; such as, ‘Why me? Why now?’ (Bury 1982: 174). Furthermore, the reorganisation of friend and family relationships (which Bury describes as ‘the mobilisation of resources’) can also be construed as being shaped by embodied experience; for example, as the result of the ‘functional limitations’ (Bury 1982: 175) which the chronically ill body may impose on the individual’s mobility, and as a result of the stigma and social embarrassment arising from impairment.

Despite this implicit focus on embodied experience, attempts to explore how the impaired body is constructed in relation to the bodies of others, is not addressed in detail by Bury. His analysis, however, does suggest that body relations play an important role in shaping illness biography. Bury highlights, for example, how participants assumed that their predisposition to RA ‘must be inherited or carried in the blood’ (1982: 174) and how ‘interviews often turned on questions about familial transmission, both in terms of whether the condition might have been inherited and whether it might be passed to offspring’ (1982: 174). Whilst subsequent studies have sought to explore the role of family relationships in shaping experiences of biographical disruption (e.g. Radley 1989; Wilson 2007) these have focused largely on exploring relations between selves as opposed to bodies. Hence, the familial and the embodied aspects of illness biography continue to be treated as separate entities. The nature of the relationship that may exist between the two, therefore, is an area in need of further research.

Around a decade after the publication of Bury's paper, sociologists began to turn their attention to the social dimensions of the new genetics. These developments occurred principally in the wake of the Human Genome Project (Conrad and Gabe 1999). Since then, the impact of new genetic technologies on patients' sense of self has been explored extensively, with several authors suggesting that the rise of the new genetics has led to new forms of biological subjectivity emerging (Kerr 2004). Specifically, it has been suggested that the rise of genetic medicine has facilitated more 'somatic' (Novas and Rose 2000) and 'inter-dependent' (Kenen 1994) constructions of selfhood amongst those genetically at risk of disease. Thus, it has been argued that genetic identity is characterised by a sense of embodied obligation (Howson 1998) or genetic responsibility towards others, where one's own selfhood is defined in close relation to the selves of others (Hallowell 1999). As Novas and Rose argue:

'Genetic identity is revealed and established only within a web of genetic connectedness, which is overlaid upon a web of family bonds and family memories, with their burden of mutual obligations and caring commitments, and with all the ethical dilemmas they entail. In becoming part of a genetic network, the subject genetically at risk may re-think their relation to their current family – lovers, potential and actual spouses, children, grandchildren and so forth – in terms of the issues of risk and inheritance. They may reshape their form of life – lifestyle, diet, leisure activities, alcohol, smoking – in these terms, which also reshapes their relations with those with whom they interact.

Novas and Rose 2000: 490

Novas and Rose's description of the web of genetic connectedness portrays a detailed and sophisticated account of the familial aspects of genetic identity. Whilst this is the case, an appreciation of the ways in which genetic identity is influenced by relations between bodies, located within the web of genetic connectedness, remains under-developed. This, we argue, is due to Novas and Rose's implicit treatment of the body as an independent and discrete unit of analysis. Such an approach reflects Western notions of the embodied-self, as located within an individual corpus. Selfhood, however, as previous empirical research has shown, may be experienced in ways which transcend the boundaries of individual bodies (Lawton 2000). As such, understanding how the relationships and inter-connectedness between bodies may serve in the construction of genetic identity is an area in need of further research.

In this paper, we explore how the concept of inter-embodiment may advance sociological understandings of genetic identity. In so doing, we also explore how inter-embodiment may advance contemporary approaches to illness biography.

Inter-embodiment

Our approach to inter-embodiment draws heavily on the seminal work of Merleau-Ponty as well as the contemporary feminist writings of Weiss and Springgay. Merleau-Ponty rejects Cartesian mind-body dualism, arguing that consciousness, and therefore knowledge, is rooted in embodied existence (Crossley 1997; Priest 1998). The body, he argued, is 'chiastic' in nature and (as such) must be conceptualised as simultaneously sentient (capable of acquiring knowledge) and sensible (the object of knowledge acquisition). As Merleau-Ponty (1968: 137) states:

‘... our body is a being of two leaves, from one side a thing among things and otherwise what sees them and touches them; we say, because it is evident, that it unites these two properties within itself, and its double belongingness to the order of “object” and to the order of the “subject” reveals to us quite unexpected relations between the two orders.’

Merleau-Ponty’s conceptualisation of the body as simultaneously object and subject, is at the heart of his approach to intercorporeality. Intercorporeality refers to the position that an external world exists and that our embodied experiencing of it is a shared enterprise. His writings on intercorporeality are, arguably, some of the most significant of Merleau-Ponty’s many contributions to contemporary body theory (Crossley 1995; 1997). Merleau-Ponty argued that an inescapable nexus exists between the objective world and our subjective experiences. He described this nexus as the ‘Flesh of the world’ (Merleau-Ponty 1968). The term Flesh is not intended to refer to physical matter but rather to an ‘element of Being’ (1968: 139) for which conventional philosophy has no equivalent. It is the Flesh of the world which creates coherence between our objective existence and subjective experience, as it represents ‘the coiling over of the visible upon the seeing body, of the tangible upon the touching body’ (Merleau-Ponty 1968: 146). Hence, according to Merleau-Ponty, it is through Flesh that intercorporeal relations between bodies are made possible.

Merleau-Ponty’s focus on the feeling body - as opposed to the ‘autonomous rational I’ (Springgay 2008: 22) - as that through which knowledge is formed is central to notions of inter-embodiment. Inter-embodiment highlights that embodied knowledge is constructed not *within* bodies, but rather through Flesh; that which unifies bodies as

objects and subjects, and which ‘weaves relations’ between bodies (Merleau-Ponty 1968: 260). As such, embodied knowledge is constituted and reconstituted through our engagement with the bodies of others. As Weiss (1999: 5) argues, ‘the experience of being embodied is not a “private affair,” but is always mediated by our continual interactions with other human and non-human bodies’. Springgay (2008: 22) similarly argues that, ‘How we come to know ourselves and the world around us, our subjectivity, is performed, constructed, and mediated in relation with other beings.’

By foregrounding the role of Flesh, and of ‘relationality’ (Springgay 2008), in the acquisition of embodied knowledge, inter-embodiment has clear potential for addressing the theoretical limitations inherent in contemporary approaches to illness biography and genetic identity. In the remainder of this paper, therefore, we explore how our participants’ experiences of acquiring knowledge about their bodies as affected by a hereditary disorder of cholesterol metabolism (familial hypercholesterolemia) may be understood from this perspective.

What is Familial Hypercholesterolemia (FH)?

Familial Hypercholesterolemia (FH) is a dominantly inherited genetic condition which causes elevated serum cholesterol levels and affects approximately one in every 500 people (DeMott et al. 2008). Individuals with FH are at significantly increased risk of premature death as a result of early onset cardiovascular disease (CVD). FH leads to a greater than 50% risk of CVD in men by the age of 50 and at least 30% in women by the age of 60 (DeMott et al. 2008; Slack 1969). The main bodily signs of FH are cholesterol deposits which are located on the tendons (xanthomas), around the eyes (corneal arcus), and on the eye lids (xanthelasmas). A

clinical diagnosis of possible or definite FH is made by measuring the patient's serum cholesterol levels, exploring their family history of high cholesterol and/or early onset CVD, and identifying tendon xanthomas on either the patient's body or on the body of a first or second degree relative (Scientific Steering Committee on behalf of the Simon Broome Register Group 1991).

Current NICE guidelines (DeMott et al. 2008) identify DNA testing as the preferred method of diagnosing FH. This is because identifying a known gene mutation can reduce diagnostic ambiguities (Humphries et al. 2006) and aid diagnosis amongst relatives (Leren 2004). Given the risks of CVD, the effectiveness of statins, and the fact that the majority of affected individuals are undiagnosed (Neil et al. 2000; Marks et al. 2004), cascade genetic screening programmes have been developed in a number of European countries; including the Netherlands (Umans-Eckenhansen et al. 2001), Spain (Pocovi et al. 2004) and Norway (Leren et al. 2004). These programmes involve index patients with definite or possible FH being asked to undergo DNA testing and their family members contacted should a known mutation be identified. FH genetic cascade screening programmes have recently been introduced in the UK, both in Scotland (Finnie 2010) and Wales (Datta et al. 2010) and extending provision of DNA testing in England has recently been recommended (Pederson et al. 2010).

Methods

We conducted in-depth interviews with patients from the Lothian region of Scotland who took part in the nationwide FH DNA screening programme. As part of the programme, patients who attended specialist lipid clinics within NHS Lothian, who had a diagnosis of possible or definite FH, were asked to provide blood samples for

the purposes of genetic testing. If a gene mutation was identified, patients were referred to a genetics clinic to discuss their results and to identify at-risk relatives (Finnie 2010). If a gene mutation was not identified, patients received a letter from the lipid clinic informing them that their results were inconclusive (as a negative DNA result does not rule out FH amongst index patients), and recommending that they encourage family members to monitor their cholesterol levels (see Hallowell, Jenkins et al. 2011).

Patients from the screening programme were recruited using an opt-in procedure. One hundred and fourteen patients with DNA results - as well as the one patient listed on the clinical database as having formally declined genetic testing - were contacted between May-December 2010, either by letter or face-to-face (total n=115). Each patient received an information sheet outlining the study, an expression of interest form and a stamped addressed envelope. Patients who wished to opt-in to the study were asked to complete the expression of interest form and return it to the research team. Of the 115 patients contacted, 43 opted-in, all of whom had consented to genetic testing and had received their DNA results. Of these, 38 patients were interviewed. One participant was excluded as they were outside the inclusion criteria and four were unavailable for interview. The majority of participants were female, over 45 years of age and came from educated, non-manual backgrounds (See table 1)

Table 1 here

A series of observations were conducted at the lipid and genetics clinics, as were in-depth interviews with key health professionals working within them; 37 patient

consultations were observed and 8 health professionals interviewed. These were conducted in order to gain insight into how the care of FH patients was managed; to explore patterns in doctor-patient interactions; and to explore how genetic testing and contacting family members were broached with patients. Findings from the health professional interviews and clinic observations were fed into the development of the patient interview topic guide, and were also used to contextualise and interpret patients' accounts.

Patient interviews were conducted between June - December 2010. With the exception of one interview that was conducted online, using instant messaging, and took over 4 hours, these ranged from 48 to 116 min. Interviews explored: experiences of discovering high cholesterol; personal and familial disease histories, experiences of genetic testing; and, the impact of DNA results on disease perceptions. The interviews were digitally recorded, transcribed and analysed using an inductive approach, with data collection and analysis running concurrently (Strauss and Corbin 1990). Interview transcripts were systematically compared in order to identify cross-cutting themes and highlight common experiences. Themes which emerged in early interviews were thus explored in-depth in subsequent interviews. During data collection, transcripts were reviewed regularly and independently by core members of the research team, who met to identify common themes and discuss areas of agreement and divergence. A coding framework was developed to capture data relating to the primary research aims as well as emergent themes. Data collection ceased at the point where no new themes were identified. NVivo 8 (Victoria, Australia) was used to manage the data.

Results

Participants' accounts highlighted the role of bodies-in-relation (where the status of the body is defined in close reference to other bodies) in the construction of knowledge about high cholesterol. Whilst knowledge of family members affected by high cholesterol and/or CVD often prompted participants to get their own cholesterol levels checked, the discovery of cholesterol deposits on their own bodies prompted participants to re-interpret the markers visible on the bodies of their relatives. Participants' understandings of the inter-connectedness of their and their family members' bodies was central in their accounts of receiving DNA results. Whilst positive DNA results could re-enforce participants' sense of a familial disease biography and of a shared 'family corpus', inconclusive DNA results could result in a sense of biographical disruption. This was because inconclusive results challenged participants' understandings of the cause of their condition, which prompted them to question why they had high cholesterol.

Discovering and interpreting high cholesterol: the role of bodies-in-relation

In contrast to other chronic health conditions, hypercholesterolemia does not usually produce incarnate sensations (such as excessive tiredness or thirst) that may trigger an awareness of the disorder's existence. In this context, some participants specifically highlighted how having high cholesterol was, from their embodied point of view, invisible.

P - Cholesterol's a kind of hidden thing ... I'm sure if you've got high blood pressure ... I imagine you feel on a day-to-day basis you maybe feel lethargic or, I don't know how people with high blood pressure feel. But, you know,

it's [hypercholesterolemia] not a disease that has any symptoms, or is a condition that has any symptoms, that it makes you feel ill or anything ...

[FH40: Male, aged 41]

Given the 'hidden' nature of hypercholesterolemia, the most consistent factor which first alerted participants to their condition was not the presence of pain or dysfunction within their own bodies, but seeing other family members die or become seriously ill as a result of developing CVD. Thus, participants' accounts frequently highlighted how the premature death of a parent, grandparent or sibling had first prompted them to consider their own potential vulnerability to CVD and to seek medical advice.

I - ... could just tell me, just in your own words really, about how you first found out you had high cholesterol, how the genetic test came about, your sort of story, I suppose?

P - Ok. Well, I, my mother died when she was in her mid-fifties of coronary thrombosis. I mean, it was a long time ago so cholesterol wasn't really a big issue in those days ... But I wondered. I always wondered whether I had, whether the cholesterol was affecting me

[FH16: Female, aged 65]

Whilst incidences of CVD and premature death in the family often led participants to access cholesterol screening, experiences of attending specialist lipid clinics were instrumental in promoting understandings of high cholesterol as running across the family. Our observations of the lipid clinics highlighted that a standard procedure

was followed for each new patient being seen. The following extract from a set of clinic observation notes summarises the nature of these consultations:

The consultations began with the doctor reviewing the patient's diagnosis/disease history and the reason(s) for their referral. This was followed by both open and more targeted questions about the patient's current state of health and any experiences of illness symptoms. A brief family history was then taken for each patient, focusing on the patient's current family status (married, children etc) and on any experiences of CVD amongst their parents, grandparents, aunts and uncles etc. The patient's lifestyle was then discussed (including occupation, alcohol and tobacco usage, diet and level of physical activity) and current medications checked. This was followed by a physical examination which included checking the patient's pulse (at neck, waist, groin), and for any signs of xanthomas.

(Extract from clinic observation notes: 28th April, 2010)

Being physically examined in the lipid clinic could result in patients developing an awareness of markers visible on the surfaces of their bodies (xanthomas, corneal arcus, xanthelasma) as being the bodily manifestations of high cholesterol.

P - When I was examined first at the lipid clinic I had a, oh, what's it called, is it an xanthoma or something? A large lump on my Achilles tendon. Now, I had gone to the GP about that on several occasions and they had said, "Oh, it's

just tendonitis”, because I used to do lots of hill-walking and bag munros¹ and things. So I was rather shocked.

[FH31: Female, aged 60]

Such re-interpretations of their own bodies led these participants to examine and re-interpret the bodies of family members, as they made connections between the cholesterol markers under their own skin and the signs located on the bodies of their relatives.

P - [The doctor] started explaining about the lumps in my fingers and the ones in my knees and the ones in my heels. And that’s what he said that these are all linked to high cholesterol. And I remember my mother, she had them in her eyes – some people have them in their eyes, they’re up here on the lid and they’re yellow. I’ve never had that, right enough, but I know that that is part of high cholesterol as well.

[FH38: Female, aged 61]

P - I also have circles round my eyes that are a colour and my dad had that, not that they ever thought it was anything to do with cholesterol. That was obviously what came in later on when they explained that was a sign of high cholesterol. We just used to think my dad had funny eyes, you know.

[FH35: Female, aged 52]

¹ Munros are mountains in Scotland over 3000ft and are named after Sir Hugh Munro, who first catalogued them. ‘Bagging munros’ refers to the practice of climbing each of the 283 munros in Scotland.

This new understanding as to how cholesterol could manifest itself upon the surface of the body prompted some participants to encourage relatives, who were perceived as having similar body markers, to get their cholesterol checked.

P - when I first noticed my cholesterol, I got little spots round my eyes, little white spots, and that's what he's [father] got round his eyes and I'm like that, "You need to go and get your cholesterol tested".

[FH41: Female, aged 18]

P - I said to (name) to go and get tested because she had, you know how you get these, like, fatty blisters just at your eyes and I thought that was a, em, sort of symptom ...

[FH24: Female, aged 67]

Interpreting the risks of having high cholesterol

Although the extent of participants' family histories of CVD varied, all highlighted at least one relative with either elevated cholesterol levels or who had died prematurely as a result of developing CVD. Whilst this was the case, perceptions of risk associated with having high cholesterol appeared to be influenced, at least in part, by prior experiences of, and exposure to, affected bodies. Some participants, for example, described how traumatic experiences of seeing parents suffer poor heart health had had a strong impact when it came to assessing the threat which having high cholesterol posed to them.

P - I suppose when I first heard I thought, Oh right. High cholesterol, what does it mean? And then when I did find out what it meant it did make me think, Oh God, that's it, I've got a life sentence! You know, I'm not going to get past sixty. Dad never got past sixty.

[FH05: Female, aged 47]

P - I did know what it [cholesterol] was and I had heard about it and I knew my mum had it and I knew I had it... I probably never realised maybe how dangerous it was and how important it was until my mum took her heart attack, and I was 21 the first time I took it really, really serious was probably at my first [lipid clinic] appointment. I was kind of a bit freaked out about getting an ECG and stuff like that, you know, just all the basic tests that they do on your first appointment. Because I did think to myself, Oh my goodness, I'm only 29! And I'd seen my mum getting ECGs and stuff like that with her heart problems that she had and yeah, it kind of freaked me out a bit.

[FH34: Female, aged 29]

Whilst experiences of seeing family members die or suffer ill health as a result of developing CVD could lead participants to emphasise the vulnerability of their own bodies, limited exposure to CVD-related deaths in the family could also be a factor in participants viewing cholesterol as (personally) less-threatening.

P - I suppose the link I was making in my mind then was young deaths from cardiovascular disease were associated with high cholesterol yet bizarrely I

seemed to have very high cholesterol yet did not seem to have any family history of early death ... So I suppose I've received it as an intellectual risk but not really applying to me.

[FH18: Male, aged 55]

In short, participants' accounts of discovering their high cholesterol and of interpreting the risks it presented to them highlight the role of bodies-in-relation, where the status of one's own body is interpreted in close relation to the bodies of others. This inter-connectedness between bodies was central to participants' understandings of their DNA test results, which we discuss below.

FH genetic testing: Re-enforcing and disrupting constructions of the family corpus

As we have reported elsewhere, participants were receptive to the idea of taking part in genetic screening for FH. This was because their experiences of managing their cholesterol over the years, the incidences of CVD in their families, and their interactions with health professionals had already led them to the conclusion that their propensity towards high cholesterol was inherited (Jenkins, Lawton et al. 2011). As one participant explained:

P - I guess it's a bit of a different thing if you discover you've got this and you've never had a relative die of heart disease and thought you were all perfectly healthy but, you know, we know we've got that [high cholesterol] in our family.

[FH12: Male, aged 54]

Most expected that genetic testing would confirm the link between theirs and their family members' bodies. As such, obtaining positive DNA results could provide participants with a sense of biographical re-enforcement (Carricaburu and Pierret 1995). This was because positive results established definitely for participants that the propensity towards high cholesterol ran across, what we term, the family corpus. The family corpus, as an analytical term, is employed here as a means of inter-embodying Novas and Rose's web of genetic connectedness described earlier (Novas and Rose 2000: 490). In essence, the family corpus refers to lay perceptions of a shared and interdependent embodied identity that is distributed across the bodies of family members. Thus, within the family corpus, each body may be understood as a node linked to the bodies of others by "blood lines". Blood lines carry the material through which each body-node is constructed. As FH37 illustrates, it was through reference to these ties, and to the relationships between bodies in the family corpus, that participants interpreted positive DNA results as a form of biographical re-enforcement:

I - ... having this genetic test or getting that result; has that taught you anything new so much or is it things which you already knew?

P- Well, it's just confirmed exactly what you know is probably going through the family. You know, it probably is a genetic thing and, you know, if we had all been tested, fully tested, then we probably would know that this is going through the family. And it's not going to stop at me, you know, the blood line's going to go somewhere else ... I don't think it's made any changes, I know that because it has went through the family the possibilities are that it

was genetic anyway. So it's not come as a surprise or anything like that, it's something that's there.

[FH37: Female, aged 53]

The concept of the family corpus - as an inter-embodied network of genetic connectedness – also helped us to understand participants' responses to inconclusive DNA results. Whilst the major, known gene mutations associated with FH are routinely screened for in analysis, the detection rate can be less than 50 per cent (Leren 2004). Although inconclusive DNA results do not (in themselves) rule out a genetic predisposition to high cholesterol, the majority of participants who had received inconclusive results appeared to interpret them, at least to begin with, as meaning that their condition was not genetic in origin. The tendency to interpret inconclusive DNA results as meaning that a hereditary disorder is not genetic has been observed in previous research with patients who have undergone genetic testing in relation to breast/ovarian forms of cancer (Hallowell et al. 2002). Interpreting inconclusive DNA results in this fashion could lead to experiences of biographical disruption. This was because the results *dis*-associated participants' bodies from those of their family members, as the following quote illustrates:

P - ... my dad was not a well man ... I [don't] remember a lot of my father but I do remember him coming home from the hospital having had his bypass, so I remember his illness and the heart disease and to that end, I was actually quite surprised that, well, where I was couldn't be genetically linked to somebody or something else.

[FH07: Male, aged 41]

Inconclusive DNA results were experienced as disruptive because they challenged participants' beliefs that their own tendency towards high cholesterol could be located within the family corpus. Hence, in the absence of a definitive link, participants with inconclusive results were often left feeling unsure as to what was causing their condition, as they did not consider their bodies to (otherwise) be candidates for high cholesterol.

I - Right. Does that, can you say how that [DNA result] makes you feel?

P - It still doesn't answer the question about why you have got it; does it? They ruled that out, yeah fine. You can get on with the research, yeah. But it doesn't answer my question: Why do I have this? As I say, I think I am pretty healthy, I thought I was..... When I speak to people, hardly anybody can believe that I have high cholesterol. You know, as I say I'm fairly active. I'm not overweight. I watch what I eat, but if I wasn't on these statins my high cholesterol would be away off the scale; but why is it?

[FH10: Male, aged 50]

Following this participant, interpreting inconclusive results as negative could lead - in Bury's terms - to the posing of key questions, such as 'Why me? Why now?' (Bury 1982: 174). In contrast to Bury's participants, however, the posing of these questions did not originate from the onset of a chronic condition, but from the dissolution of an acceptable explanation as to its cause.

Discussion

We began this paper by arguing that the concept of inter-embodiment can advance sociological research into illness biography and genetic identity. Inter-embodiment, as developed by Weiss (1999) and Springgay (2008; 2010), highlights that embodied experiences are not ‘private affairs’ (Weiss 1999: 5) but the product of our interactions with the bodies of others. As such, inter-embodiment is rooted firmly within a Merleau-Pontian approach to the body and within notions of flesh and of intercorporeality in particular. Inter-embodiment emphasises how the material nature of our bodies plays a crucial role in determining relations between individuals and, therefore, shapes the (intercorporeal) relations through which body knowledge and self-identity are constructed.

We have explored participants’ accounts of discovering high cholesterol and of undergoing genetic testing for FH from an inter-embodiment perspective. The discovery, amongst participants, that their bodies contained high levels of cholesterol often stemmed from their knowledge of the bodies of family members, especially those who had died from CVD. This knowledge prompted participants to consider their own vulnerability to future ill-health. Experiences of attending lipid clinics re-enforced understandings of high cholesterol as running across the family. This was because, through their interactions with specialist doctors, participants could arrive at interpretations of the lumps, spots and rings on the surfaces of their bodies as being the bodily manifestations of high cholesterol. These discoveries prompted participants to make connections between their own body markers and the lumps, spots and rings visible on the bodies of their relatives. Such doctor-patient interactions aided the construction of a *familial* disease biography in which hypercholesterolemia was spatialized (Foucault 1973) across the bodies of the family.

In this context, genetic testing for FH was viewed as a means of confirming existing, inter-embodied understandings rather than offering new insights into participants' condition. Hence, participants who received positive DNA results tended to experience these as a form of biographical re-enforcement (Carricaburu and Pierret 1995), whilst those who received inconclusive results (and who interpreted them as meaning that their condition was not genetic) experienced a degree of biographical disruption (Bury 1982). This was because, whilst positive DNA results definitely located participants' predispositions to high cholesterol as running across the bodies of the family, inconclusive results challenged participants' existing assumptions that their bodies could be understood in relation to the bodies of their relatives.

What, then, does the concept of inter-embodiment add to understandings of illness biography, and of genetic identity? Because inter-embodiment emphasises that body knowledge and self-identity is constructed via the interaction which takes place between bodies, it serves to highlight that experiences of biographical disruption (or biographical re-enforcement) are processes in which the bodies of others play an integral role. Previous authors (e.g. Hubbard 2010; Wilson 2007) have highlighted the need to consider the utility of biographical disruption within the various contexts in which illness is experienced. Research from within the illness biography tradition often draws a distinction between the familial and the embodied aspects of illness biography, which (arguably) has little resonance when exploring experiences of disorders that are believed to have a hereditary cause. In the case of genetic forms of disease, research has highlighted that the biographies and anticipated life trajectories of individuals are often intricately connected to the biographies and trajectories of family members (Cox and McKellin 1999; Featherstone et al. 2006). Previous

research into lay understandings of coronary heart disease have highlighted how susceptibility to poor heart health is often viewed as an inherited trait, and that experiences of witnessing family members die or become seriously ill as a result of developing CVD can lead individuals to consider, and to emphasise, their own vulnerability to the disease (Davison et al. 1989; Emslie et al. 2003; Walter et al. 2004). In this context, an individual's discovery that they are affected by a genetic disorder which increases their risk of cardiovascular disease can provide a degree of biographical re-enforcement (despite its potential implications for the individuals' own future health) when vulnerability to heart disease is believed to be an integral aspect of the wider family story. As such, and following Finkler (2000), genetic testing for conditions such as FH may contribute to the developing familial narrative, facilitating feelings of mutual connectedness and a shared (embodied) identity.

In this paper, we introduce the concept of the family corpus in order to highlight how a shared embodied identity was drawn upon by participants in the interpretation of their DNA results. The concept of the family corpus is not intended as a radical departure from current theorising on lay understandings of the new genetics. Rather, it highlights how bodies play a crucial role in shaping what Novas and Rose describe as the web of genetic connectedness, within which individuals 're-think their relation to their current family ... in terms of the issues of risk and inheritance' (Novas and Rose 2000: 490). As such, we hope that the concept of the family corpus may advance future discussion of genetic identity, of genetic responsibility, and of selves-in-relation, by considering the role of bodies-in-relation, as well as how illness and self-identity may be experienced in ways that transcend individual bodies.

Whilst inter-embodiment may have a role to play in advancing research within the sociology of health and illness, it must be noted that inherited disorders, especially those which produce visible bodily manifestations, may be particularly amenable to this approach. Clinical criteria for diagnosing FH, for example, rely heavily on the body status of a patient's relatives, thereby actively promoting consideration of other bodies in the diagnostic process. Weiner (2009: 415) highlights how FH patients frequently distinguished between their own 'inherited cholesterol' and the 'ordinary cholesterol' experienced by non-FH patients and which is attributed to poor diet and lifestyle practices. Whilst this is the case, Weiner (2010) argues that for her participants at least, narratives of FH were not highly influenced by experiences of family members or by a shared sense of identity. As Weiner states:

'... people's talk about their experiences of FH does not suggest a strong sense of collective identity based around the condition.... many interviewees either did not discuss family history or talked of piecing family health histories together after their own diagnosis was established.'

Weiner 2010: 3

Weiner's finding that participants often did not discuss their family histories, or may not have been particularly aware of a familial propensity to CVD prior to diagnosis, is in stark contrast to our own findings. As we have highlighted, the majority of participants reported discovering their high cholesterol as a result of their family histories. Furthermore, mention of family members is a cross-cutting theme which runs through the interview extracts we have presented. It is possible that differences between our findings are, in part, a product of differing research designs. Our

participants, for example, were asked to discuss their family histories in-depth during the interviews, and family pedigrees were taken down by the researcher, which may have resulted in a more explicit focus on family members than was the case in Weiner's study. However, patients' experiences of FH are likely to be influenced heavily by their interactions with health professionals (Will, Armstrong et al. 2010). As such, experiences of undergoing DNA testing and of attending lipid clinics which place a strong emphasis on exploring family histories of CVD, are likely to have played a pivotal role in highlighting to our participants, the significance of family members' bodies. As Table 1 highlights, approximately half of our participants came from professional, non-manual backgrounds. As we have argued elsewhere (Jenkins, Lawton et al. 2011) this is similar to Weiner's study and is likely due to low numbers of patients from manual backgrounds attending specialist lipid clinics. All patients who took part in the current study had consented to genetic testing and had received their DNA results. As such, it should be noted that the accounts of patients who decline genetic testing (or who do not attend specialist lipid clinics) could be very different to those presented above.

The exploration of inter-embodiment from within the sociology of health and illness is in its infancy. In this paper, we have demonstrated how inter-embodiment aided understandings of patients' accounts of discovering high cholesterol and undergoing genetic testing for familial hypercholesterolemia (FH). Other medical sociologists could usefully explore alternative ways of defining, and applying, the concept of inter-embodiment within our (sub) discipline.

Acknowledgements

We would like to thank all the patients who took part in the study, as well as the staff at all of the clinics that assisted us; in particular, Dr Simon Walker, Dr Bob Finnie, Prof Mary Porteous, Catriona Whyte, Dr Suzanne Mackenzie and Tricia Livani. We are grateful to Lesley Gardner, Lisa Horsburgh and Rosa Bisset whose secretarial and administrative skills were invaluable to the successful running of the project. The research was funded by a grant to Nina Hallowell, Margaret Douglas and Julia Lawton from the Chief Scientist's Office. We would also like to thank Dr Martyn Pickersgill, Dr Emma Rawlins, Neneh Rowar-Dewar, Dr Amy Chandler and Dr Catriona Rooke for their insightful and constructive comments on an earlier version of this paper.

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Table 1: Participant characteristics

	N
i. Age (yrs) at interview	
Mean	52.63
Youngest participant	18
Eldest participant	67
45 years \leq (%)	8 (21)
ii. Gender (%)	
Female	21 (55)
Male	17 (45)
iii. Education (%)	
Compulsory education	14(37)
Further education	4(11)
Higher – HNC/HND	4(11)
Higher – Degree/Postgraduate	16(42)
iv. Current/most recent [main] occupation (%)	
Professional and Managerial	11(29)
Skilled non-manual	9(24)
Semi-skilled non-manual	11(29)
Skilled manual	2(5)
Semi-skilled manual	1(3)

Routine manual	2(5)
Other/unclassified	2(5)
v. Mutation status (%)	
Mutation identified	23 (61)
No mutation identified	15 (39)
vi. Clinical genetics	
Attended genetic counselling	15 (39)
vii. Estimated years attending specialist lipid clinics (%)	
0-2	11 (29)
3-4	7 (18)
5 -9	7 (18)
10+	13 (34)
Notes	
Figures principally based on patient self-report data	
Percentages are to the nearest whole number	